DOCUMENT RESUME

ED 389 137 EC 304 424

AUTHOR Miller, Joan E. Heller
TITLE Living with Hearing Loss: A Lifelong Educational Process--A Parent's Perspective.
PUB DATE 16 Jul 95
NOTE 19p.; Paper presented at the International Congress on Education of the Deaf (18th, Tel Aviv, Israel, July 16-20, 1995).
PUB TYPE Viewpoints (Opinion/Position Papers, Essays, etc.) (120) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Child Rearing; Communication Skills; Coping; *Deafness; Elementary Education; Inclusive Schools; *Mainstreaming; Oral Communication Method; *Parent Child Relationship; *Parent School Relationship; Personal Narratives; Preschool Education; *Social Integration; Special Classes; Total Communication

ABSTRACT

The mother of a deaf child recounts her family's experience from her daughter's infancy to her successful adjustment and high achievement in elementary school. Worries during the child's infancy and reaction to the diagnosis at 18 months are documented, as are the mourning p-ocess and choosing an educational approach, in this case mainstreaming. The child was first enrolled in an oral/aural parent-infant program, which was later combined with a regular community nursery school program. This combined approach of a smaller "self-contained class" plus a "larger mainstreamed class" was continued in kindergarten while the family became educated in sign language and the deaf culture. In first grade the child was fully mainstreamed, with cued speech used to supplement her predominantly oral education. Her successful adjustment in the mainstream elementary program was felt to be aided by the fact that her parents taught her hearing coaches, teachers, and friends how to communicate with a severely hard-of-hearing person. The importance of fully integrating the deaf child into family conversations is stressed. Suggestions are offered to facilitate the child's transition from elementary to middle school, including advocating for the deaf, cultivating social ties within the deaf community, utilizing social support groups, using assistive listening devices, obtaining professional counseling, and meeting adult deaf and hard-of-hearing role models. (DB)

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ED 389 137

Living With Hearing Loss: A Lifelong Educational Process
A Parent's Perspective

Joan E. Heller Miller, Ed.M.
4917 Waterfowl Way, Rockville, Maryland 20853
U.S.A.

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LIVING WITH HEARING LOSS: A PARENT'S PERSPECTIVE

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Abstract

This is a personal account of one parent's discovery of how living with a severe hearing loss in a hearing society is a dynamic, life long educational process. Together, the youngster with hearing loss and her parents embark on a journey of adaptation and accomodation at each successive stage of the child's development impacted upon considerably by the hearing loss. The parent must continue to learn, and make informed decisions with the help of appropriate professionals about amplification, communication methodologies, educational settings, and assistive technology. Emotional, social, and psychological aspects of hearing loss must also be addressed by the youngster with hearing loss and her parents. This includes identification with the deaf world, the hearing world or a combination of both. Suggested learning skills and parent empowerment strategies are offered to families sharing similar experiences.

Living With Hearing Loss: A Lifelong Educational Process
A Parent's Perspective

On behalf of my family, I'd like to take you on a sailing excursion, sharing with you my perspective not only as a professional in the field of education, but as a parent of an eleven year old who is severely hard of hearing since birth.

First, the subject: Our daughter, Cara, the oldest of our three daughters. Next, Cara's telling audiogram, indicating severe to profound, bilateral, sensorineural hearing loss which so far has remained unchanged over the last ten years. Finally, her academic and extra- curricular achievements to date: "Straight A's", or excellent marks in all her major school subjects at the end of her elementary school years, elected school Vice President and Safety Patrol guard, gifted artist, athlete, and drama enthusiast.

How did we get from that discouraging audiogram to her developmental achievements to date?

WE MISSED THE BOAT! (PRE- IDENTIFICATION STAGE)

At the very beginning, we drifted with our infant daughter through a vaguely outlined, foggy coastline of pre- diagnostic anxieties which manifested themselves as formless, but dreaded, concerns that certain things were "not quite right". During her first eighteen months of life, we whispered our shared fears to each other, began to call out, and finally, began shouting to our pediatrician, "What's wrong with our

child?" Because our pediatrician continued to dismiss our concerns with friendly reassurance, no one in our family wanted to pursue the pessimistic path of insisting we seek further professional advice. Yet, why was her language development proceeding so slowly? Why did we have to clap our hands to get her attention? Why was she always singing so loudly? Why wasn't she learning as quickly as we thought she should be? Was she Deaf?... Mentally Retarded? Even Childhood Psychosis and Autism crept into our minds as dreaded possibilities.

STARTING TO CHART OUR COURSE (IDENTIFICATION STAGE)

Finally, at eighteen months, an audiogram and diagnosis. Having to face the news... "Your child cannot hear", was the announcement.... Having to break the news to grandparents, still basking in the joy of receiving their first grandchild..."A severe to profoundly deaf child". Who, in our family could begin to make sense of this? A deaf, healthy child born to a deaf family is a joy. Deaf parents know about deaf children. They welcome it in their children.

My husband and I, who had the advantage of hearing all our lives were unprepared for this journey. We, and most other young hearing parents we had met regarded deafness as a disaster - a cruel fate in life.

Where were we to turn? There seemed to be no one *right* direction to turn in. Advice and comments, invited or not, poured forth from numerous sources. Opinions were often conflicting, and sometimes adversarial.

Each family member needed to go through the mourning process of giving up the dream of the perfect child with whom we thought we were blessed. This included the fascinating stage of denial. Cara's paternal grandparents immediately inquired, "How long will she have to wear those hearing aids?" And even many years later, they recommended, "We think you should take down that automobile safety sign that says DEAF CHILD on your street. You're *turning her into* a Deaf Child."

CHOOSING AN EDUCATIONAL APPROACH

We wondered about educational options. Mainstreaming a child with a severe to profound hearing loss is not always the easiest or best course, and there can be many good reasons for *not* mainstreaming. But what was best for our child?

My husband and I could not bear the thought of "sending our daughter away" to be educated at a residential school for the Deaf. If it

were at all possible, and for as long as it might be so, we wanted the pleasures and challenges of raising our own daughter, in her own home, in our own care, and to the best of our loving ability. We set out to prove to ourselves that mainstreaming a severely hard of hearing child was perfectly acceptable and even, desirable.

LEARNING ABOUT MAINSTREAMING

Mainstreaming a severe to profoundly hard of hearing child is a difficult and complex undertaking. Educational and psycho-social choices and solutions are often subtle, rather than clear-cut. They require using PARENT EMPOWERMENT STRATEGIES at each stage of the child's development.

It was only after applying these strategies- gaining knowledge about deafness and different communication methodologies by studying and by consulting with deaf and hearing laypeople and professionals, assessing, and continually re-assessing our progress, and acting as an advocate for our child that we decided to set sail on a mainstream course.

In brief review of the ages and stages of Cara's education, we begin at the **Parent/Infant and Nursery School** when at the age of eighteen months, we enrolled her in an oral/aural Parent-Infant program within our local school district in Rockville, Maryland, about forty minutes outside of Washington, D.C. Factors which convinced us to set sail on this path were:

1. Cara had good use of residual hearing with amplification (two hearing aids which she quickly learned to tolerate and then grew to love, and soon thereafter, a personal FM auditory trainer.)

2. By twelve to eighteen months, Cara had already begun to develop extremely "intelligible speech"; she was easily understood by family, friends, and new acquaintances. Her receptive and expressive language was growing in leaps and bounds.

Using a combined special education (self- contained classroom) and regular education (mainstream) approach, we focused on auditory training, speech, and socialization skills. Three mornings a week we went off to school together for hard of hearing infants and their parents where we received invaluable lessons in speech and language enrichment. By her second birthday, the other two weekday mornings a week, Cara was placed in a community hearing nursery school program to help build her mainstreaming skills.

KINDERGARTEN

Because this concept of a smaller "self- contained class" plus "larger, mainstream class" approach was working well for her, we decided to stay with this same, combined approach in kindergarten. As we look back at that first, early learning stage, we have no regrets.

During her early pre- school years, we also began to realize that the most effective method for Cara to acquire information was not clear-

out all of the time. If given her choice, she would prefer to get by in the mainstream, hearing world solely by listening with her residual hearing, and by speechreading.

We observed, however, that these aural/oral techniques only work adequately for her however, under optimal circumstances. These include times when her hearing aids are on, when she is within a couple of feet from the speaker, and when there is no, competing background noise. When her hearing aids were off, Cara's hearing loss crossed over the fence, into the world of the profoundly deaf.

PRE-SCHOOL SAILING- SIGN LANGUAGE

After evaluating both the limitations, and the progress she had made in these critical, language building years, we decided to learn more about supplemental communication choices to help fill in the gaps of any receptive information she might otherwise miss. We were fortunate to have a wonderful teacher from the local, school for the deaf come to our home for a couple of hours each week during Cara's nursery school years. She began educating our family about sign language and the deaf culture, and helped teach us how to further enrich Cara's language skills through play.

ELEMENTARY SCHOOL SAILING- CUED SPEECH

By the end of her formal, pre- school years, we had learned that with continued support and effort, Cara could be a mainstream success.

Why not supplement her predominantly oral education with an additional language learning system - Cued Speech?

For those of you unfamiliar with Cued Speech, it is a phonetically based, oral method of communication, developed for use with and by the aurally challenged, in which eight hand configurations in four positions of either hand are used to supplement the visible manifestations of natural speech. Because most sounds look alike on the lips, the purpose of Cued Speech is to overcome the limitations of pure oralism in receptive communication.

We learned through our research that Cued Speech kids attain extraordinary language skills, improve their speechreading abilities, are avid readers, and clearly succeed in the hearing mainstream using this approach. During our journey thus far, we had clearly adopted the philosophy," More must be better".

Beginning in first grade, Cara was fully mainstreamed at our neighborhood, public elementary school with a cued speech transliterator to give her what we considered to be the optimal language learning opportunity.

SAILING COMFORTABLY IN THE MAINSTREAM SOCIALLY

During her elementary school years, although Cara was a "mainstream success" beyond our expectations, we learned that there were certain actions required to insure her psycho-social success in the mainstream as well. Cultivating opportunities to share common experiences with hearing children in neighborhood, school, and after school, extracurricular activities serve as the glue which bond young children together. Fully participating in Girl Scouting, after-school functions, county team sports, school and community theater productions, etc. have all been enjoyable self- esteem building activities for Cara over the years.

MAINSTREAMING OTHERS AROUND US

It's been a real lesson for us to learn how to teach her hearing coaches, peers, and playmates how to communicate with a severely hard of hearing person. We call this responsible mainstreaming. Practicing useful communication techniques have allowed her hearing coaches, teachers, and friends to give her the skills and confidence to integrate her effectively into mainstream activities such as summer camps, Girl Scouts, sports, or special events like public sightseeing tours, museums, theater, or the movies.

Equally, if not more important is mainstreaming her into family conversations, or, "In each home with three or more young children all needing their Mom at the same time, a spouse who's a doctor and needed by his patients constantly on the phone when he is home, a doorbell, and other miscellaneous acoustic stresses and strains, there develops a "Tower of Babble".

My two other hearing children, and my husband can understand me without giving me their full attention. I can be passing the plates of food onto the dinner table, walking towards the front door to answer someone's knocking, head towards the constantly ringing telephone, or glance at the newspaper while listening, or while talking to one of my hearing family members all at the same time.

But with Cara, I must STOP whatever I'm doing, get her full attention, and continue to face her completely so she can read my lips, speak distinctly, or throw in a sign or cue to clarify my message when I repeat it the second time, if she doesn't get it correctly the first time. It is often a lot of effort, more than I can emotionally handle, felt especially at the end of a long day when my patience wears thin.

I register this complaint only for a brief moment though. For I then think of Cara who so courageously sets out into the world, needing to rely on her undaunted patience and determination to succeed in every moment of every day. I admire her greatly.

Why not use a supplemental, manual approach (signing, or cueing) the first time around you might ask? Up until now, Cara insists on getting by with as few outwardly noticeable accommodations as possible. In fact, she insists on oralism. "Mom, you don't have to sign or cue. That's for Deaf People." I reply, "Then you have to watch my face and read my lips". She insists, "No, I don't". And so, the debate about oral versus total communication goes on and on.

MAKING DECISIONS ON HOW TO CHART YOUR COURSE

Part of this navigational experience as a parent is learning when to tighten the sails, and when to let the sails out. During the turbulent adolescent years when the child is individuating, or asserting themselves as a person with their own identity, separate from their parents, sometimes, being the best parent means giving ourselves permission to do less.

One harsh aspect of Cara's adolescence for my husband and I is allowing for her greater autonomy, and accepting the amount of sometimes limited, auditory information she chooses to settle for. Distinguishing when my child needs additional help from an interpreter, or when she can manage by herself translates into...

"When is it O.K. to let my child be sufficiently informed versus completely informed? (or,"When is enough information truly enough?")

We notice a big difference in annual mainstream class school

photos between the beginning, compared to the end of elementary school. You could easily locate Cara in her classes early on as "the girl with the auditory trainer". That is, until fourth grade came along. Cara wanted nothing more during this time of adolescence than to "blend into the crowd" and look like of all the hearing kids in the class.

After months and months of battle, the auditory trainer finally came off. Its auditory advantages were being outweighed by its psychological disadvantages.

ADOLESCENCE- CAUGHT BETWEEN TWO WORLDS

When making a parental decision early on as we did to raise our daughter in the mainstream, and continually since that time (Cara is now eleven years old, and about to make the transition from elementary to middle school) we are constantly looking for ways to help Cara sail comfortably between the hearing, mainstream world and the deaf community.

On the one hand, we have encouraged her to develop a positive sense of self esteem, and accept herself as a young girl who happens to be extremely hard of hearing, not unlike those in the deaf community. On the other hand, we have encouraged her to develop her keen oral/ aural language skills which will help her to achieve success and happiness in the larger, hearing mainstream.

Being a severely to profoundly hard of hearing person living in the mainstream in some ways is more difficult than choosing the social

acceptance and easy communication afforded by living in the deaf community.

Feeling the wind pulling in two directions at the same time- towards the world of the hearing and towards the world of the deaf means being caught motionless in the middle, with no primary source of identification and personal sense of belonging. "Where do I comfortably fit in?" That is the question my pre- teen is now grappling with, and will have to answer for herself over the course of her lifetime.

As we are approaching Cara's middle school years, there have been numerous occasions when the increased realization of her difference, and her sense of not belonging in either group has taken a toll on her spirit. During these emotionally, stormy times we have encouraged Cara to seize any and all opportunities to help her "make lemonade out of lemons". Some ideas are:

1. **ADVOCATE FOR THE DEAF**

As a highly verbal, bright girl with hearing loss, Cara had the unique privilege of being invited to speak to legislators of the United States Congress to advocate for the legal rights of the Deaf and Hard of Hearing. This proved to be a huge boost to her self- esteem during a time when she needed it most.

2. **CULTIVATE SOCIAL TIES WITHIN THE DEAF AND HARD OF HEARING COMMUNITY**

Although Cara prefers an oral, mainstream approach, we have continued to encourage her to use sign language and cued speech during those situations which require additional receptive language assistance. Moreover, we feel that learning sign will help bridge Cara's affiliation with the deaf community, and help build her identity as a successful person with a hearing loss. As an oral, successful hard of hearing person with good signing skills, she could hopefully have beneficial leadership skills to offer to the Deaf Community.

3. SOCIAL SUPPORT GROUPS CAN HELP BRIDGE THE GAP

It was helpful to start a social support group for Cara was when she began to encounter an identity struggle in her unique position as neither Deaf, nor Hearing. This began during her preteen years when "peer acceptance", and "fitting into the social group" became an overriding concern.

In a social support group with other hard of hearing youngsters, Cara does not feel psychologically different, or socially alone. On the contrary, she fits right in with this unique, "in between" group, sailing between the world of the hearing, and the world of the deaf.

Our family has also had the privilege of discovering a unique, national organization called Self Help for the Hard of Hearing, committed to help the hard of hearing live in the mainstream. S.H.H.H. has been an invaluable support group for our family, as well as a tremendous source

of information about new technology, laws, educational practices, and a myriad of other vital concerns.

4. **ASSISTIVE LISTENING DEVICES**

There are technological and other communication accommodations Cara has needed to learn to make to adapt to the mainstream. Beginning in her elementary school years, we have encouraged her to use any and all assistive listening devices to manage more effectively in a hearing world.

These include regular use of her hearing aids, a second set of waterproof aids for swim team practice, personal FM auditory trainer, amplified telephone, vibrating alarm clock, captioned television, and reliance on the written word whenever possible. All of these independent living tools offer her the increased autonomy and independence she's been asking for in her pre-teen years.

5. **PROFESSIONAL COUNSELING**

In addition to the time when we first sought counseling when Cara's hearing loss was initially identified, professional guidance was again a Godsend for us during Cara's adolescence. At age nine or ten, for the first time she expressed tremendous anger and depression about the realization that her hearing loss was permanent. A limited number of sessions with a gifted psychologist, knowledgeable about issues in deafness helped Cara resolve some of these issues.

6. MEET ADULT DEAF and HARD of HEARING ROLE MODELS

Seeking out other ordinary, and extraordinary deaf and hard of hearing adult role models has also been helpful in teaching Cara that living with a significant hearing loss does not have to be limiting with respect to career interests or personal happiness and success.

ULTIMATE GOAL

What is our ultimate goal for Cara? A great career? A beautiful marriage and family of her own one day?... Whatever she wants. Ultimately, we must prepare our daughter for communication and relationships, so that whatever she does as she tries to reach her goal, she feels connected to others in this world.

We, as parents may think we have the final word, but we are merely the initial and not the final decision makers in our children's lives. When it comes to learning and motivation, the maturing child and adolescent actually holds the tiller for better or worse. Parents can only point the way, and try to chart the channels for safe passage.

Finally arriving at our destination (the point we are at today), I would like to underline a few of our hard learned, navigational guidelines, or coping strategies for others who may face the same crossings. Above all, living with a hearing loss is an ever- changing, life-long learning process for the entire family.

PARENTING STRATEGIES

Lesson #1- BE THE BEST POSSIBLE PARENT ADVOCATE FOR YOUR CHILD

Lesson #2- GAIN KNOWLEDGE BY RESEARCH & STUDY

Read the literature

Subscribe to professional organizations

Consult professionals

Speak to parents of other hard of hearing kids

Meet with other hard of hearing children

Meet with deaf and hard of hearing adults

Improve methods of communication accessibility

Know the laws

Seek professional counseling when necessary

Lesson #3 -MAKE REGULAR ASSESSMENTS-

Evaluate new options

Make decisions

Set goals

Lesson #4- FLEXIBILITY IS KEY

Continually re-assess progress

Set new goals

Lesson #5- BELIEVE IN YOUR CHILD AND YOUR CHILD'S FUTURE.

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I. DOCUMENT IDENTIFICATION:

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Title: Living With Hearing Loss: A Lifelong Educational Process - A Parents Perspective	
Author(s): Joan E Heller Miller, Ed. M.	
Corporate Source: Self Help for Hard of Hearing	Publication Date: July 16, 1995

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Printed Name: Joan E. Heller Miller Ed. M	Organization: Self Help for the Hard of Hearing
Address: 4917 Waterfowl Way Rockville Maryland 20853 USA	Telephone Number: (301) 9243895
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Name: Joan E. Heller Miller Ed.

Address: 4917 Waterfowl Way
Rockville, Maryland 20853 USA

Paper presented at the 16th International Congress on Education of the Deaf (Tel-Aviv, Israel, July 16-20, 1995)